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Brown, Margaret; Jack-Waugh, Anna; Sharp, Barbara; Duffy, F.J. Raymond ; MacRae, Rhoda

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## **Dementia Champions editorial for Dementia**

**Title: What are Dementia Champions and why do we need them?**

**Authors: Brown, M., Waugh, A., Sharp, B., Duffy, F.J.R and MacRae, R.**

Let us begin with a definition. A champion is a person who vigorously supports or defends a person or cause. We will argue that there is a need for people living with dementia to have champions in acute hospital and related settings. In particular, we believe that Scotland's Dementia Champions' Programme is a positive example of how to educate health and social care professionals to lead change and improve the experience for people with dementia, their families and carers.

The training of Dementia Champions is not uncontested. There have been calls for all staff to be better educated rather than focusing on upskilling some staff to become Dementia Champions. The argument is that this title can imply they are experts in dementia care. This by implication may overstate what they can do, and / or they may have unrealistic expectations placed on them. With the increasing use of the term champion in the dementia landscape and a consideration of these views we have been prompted to consider two issues: first, why we need Dementia Champions? and second, can Scotland's Dementia Champions Programme provide guidance in terms of pedagogy, programme aims and expectations and educational outcomes?

The increasing numbers of people with dementia living longer has resulted in a significantly higher likelihood that they will require care in acute hospitals. Therefore staff involved in admission, assessment, care, treatment and discharge must be responsive to both complex needs and experience of the person with dementia. To meet these often unique and complex needs the current and future health and social care workforce need to be provided with high quality evidenced informed education. However, we are beginning from a low level. The first professional preparation of many health and social care practitioners lacks theoretical and skill development for working with people with dementia (Pulsford et al., 2007, Collier et al., 2015). We know that the coverage of dementia education amongst most UK university health and social care programmes has been considered inadequate and inconsistent (Collier et al., 2015). There is a particular lack of dementia education amongst those professions who work outside mental health, this extends beyond the UK and is an international issue (Hvalič-Touzery et al., in press). Moreover, acute hospitals still predominately focus upon the treatment of physical health conditions.

Successive Dementia Champions in Scotland report a widely held view that dementia is considered the responsibility of mental health services. A combination of socialisation, lack of education and a perception that people with dementia were not part of their patient group has created a perfect storm. This has allowed stigma to take hold as people with dementia come into hospitals where the

majority of the workforce is ill equipped to work with people living with dementia (Houghton et al., 2016, Turner et al., 2017). Many studies highlight the negative impact of these experiences for people with dementia and their families, although fewer consider the distress of staff in these situations. We still hear of poor outcomes, the continuing experience of stigma and descriptions of poor practice and care. We hear less about the impact on staff, who strive to be competent and confident but are often unprepared to care for people living with dementia that are sick and frequently in crisis in their care settings.

Simply put, we need Dementia Champions to ensure the voices of the person living with dementia, their family and supporters are heard loud and clear in the complex health and social care arena. The knowledge, skills and leadership required of a dementia champion cannot yet be achieved for the whole workforce, even though all practitioners have a professional responsibility to provide excellence in care.

There is considerable variability and diversity amongst the programmes that are reported to produce Dementia Champions. A recent literature review to identify features of effective dementia educational programmes recognised that these programmes sit with complex systems where a myriad of factors including staff attributes; organisational, environmental and cultural contexts influence practice (Surr and Gates, 2017). Therefore, programmes that intend to produce Dementia champions clearly must take these issues into account. These include consideration of how Champions are educated, how this is facilitated and by whom and what is expected of them after the programme is complete. These educational outcomes must be aligned to dementia specific knowledge and skills frameworks. Importantly programme facilitators should be highly knowledgeable and skilled in dementia care and pedagogy. The preferred approach needs to acknowledge both the lack of early education preparation of many staff and the often negative perception by some of people living with dementia. It also needs to facilitate practitioners to not only unlearn but also learn together, to learn from and with people living with dementia and their families. We contend that lone staff members pursuing individual professional development is insufficient, it requires weight of numbers, a network of leaders, managers and specialists to support change and learning into practice within and across systems.

The National Dementia Champions Programme in Scotland addresses all these issues and more. The programme is situated within an infrastructure of policy, educational and practice support. People living with dementia and family carers are partners in the development and delivery of programme. It is an experiential, interactive rights based programme that uses simulation, skills and practice based learning to engage the participants' values, attitudes and knowledge. Underpinned by an

appreciative enquiry and a blended learning approach, supportive change agent materials aligned with practice areas and carefully developed assignments ensure a quality assured outcome. Participation is supported by personal tutors and Alzheimer Scotland nurse/Allied Health Professional consultants and Scottish Social Services Council staff within care settings. There are currently over 700 Champions and another 150 will graduate in March 2018. The programme is interdisciplinary and includes nurses of all grades working in a multitude of specialities, physiotherapists, occupational therapists, clinical educators, speech and language therapists, social workers and others in qualified professional roles.

So does it matter than some dementia champion's programmes do not contain all the elements of Scotland's Dementia Champions Programme? Perhaps that depends on what we, the public, their colleagues and employers expect of them? If we wish our champions to be vigorous supporters of improvement of the acute care experience of people living with dementia and their families, then surely they need a rigorous preparation. Perhaps we also need to consider what is in a name.

Until people living with dementia are fully accepted in society and not labelled as 'other', we will need Dementia Champions. Champions who have received effective preparation and ongoing support, who can bring rhetoric about living well with dementia to life and who can influence and improve the acute care experience of people living with dementia and their families.

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### **Authors**

Dr Margaret Brown, Senior Lecturer and Deputy Director, Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland

Anna Waugh, Lecturer, Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland

Dr Barbara, Sharp, Policy & Research Advisor, Alzheimer Scotland

Raymond, F. J Duffy, Programme Leader, School of Health Nursing & Midwifery, University of the West of Scotland

Dr Rhoda MacRae, Lecturer, Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland